# Will HIV-Positive People Use an Interactive Computer System for Information and Support? A Study of CHESS in Two Communities.

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**ABSTRACT**

*A study of use of an interactive computer system (CHESS -- Comprehensive Health Enhancement Support System) by HIV-Positive people was conducted in Madison and Milwaukee during Fall 1992 and Winter 1993. Computers were placed in homes, and use monitored by the computer. Results showed that the system was used heavily by both samples, and that gender (women used it more) age, (younger used it more), living arrangements (those living alone used it more), and need for health care information (those who felt the most need used it more) but not education predicted use of CHESS. The authors argue that heavy CHESS use by a wide variety of HIV-positive people suggests that the computer can overcome "information poor" barriers in health information campaigns.*

For people diagnosed with life-threatening illnesses, obtaining necessary information, making effective plans and decisions, and locating sources of support can play a key role in coping with the crisis [1-3]. However, doing so often faces considerable barriers: geography, education, finances, physical mobility, ability to act under stress, and the belief that action must be taken immediately [4]. The emergence and development of computer technology, and its integration with social systems and behavior change knowledge, offer the opportunity to overcome or reduce many of these barriers by making access to help convenient, comprehensible, timely, non-threatening, anonymous, and controlled by the user.

A computer-based support system known as CHESS (the Comprehensive Health Enhancement Support System) has been developed by a team of decision, information, education, medical, and communication scientists [5, 6]. This system not only integrates information, communication and analysis, but also uses color, graphics and simple user-prompts to make CHESS appealing and easy to use, even by people with little or no computer experience. But an interactive computer system is not really a solution to health crisis barriers unless the computers are actually used. Beyond that, a computer system runs the risk that it will be used only, or at least more, by those already most capable and advantaged. If, for example, CHESS were used by the highly educated, or by those already successful in dealing with the health care system, it might further disenfranchise the "information poor" [7]. Likewise, given current gender and age biases toward computers, a health computer might seem more intimidating to women than men, to older than younger people.

Individuals' health status and situation should also predict CHESS use. Initial diagnosis with HIV-positive status might well lead to a search for basic information and the reassurance of social support, as well as help in making decisions about treatment options [3]. At later stages of the disease, basic information should be much less important, while social support remains important and decisions may be needed in other areas, such as financial planning. More generally, physical and mental health, existing social support, and perceived needs for information should all predict CHESS use.

**The CHESS System**

HIV content in CHESS was shaped by an extensive assessment of the information and support needs of HIV-positive people. This included survey research, focus groups, and one-on-one interviews. Content was then developed and reviewed by a team of experts and by HIV-positive people to make sure that it was accurate and accessible. CHESS has three major classes of services:

**Information Services.** Questions and Answers is a compilation of answers to over 400 questions related to the medical, financial, legal, and social/sexual issues of AIDS/HIV infections. Questions can be accessed either by a key word search or through a hierarchical topic structure. Answers are brief 1 to 5 screen overviews, with references to where more detailed information can be found.

Instant Library contains over 200 articles, brochures and pamphlets selected by our team of AIDS experts. Articles cover a broad range of topics and levels of complexity, and are drawn from scientific journals, AIDS newsletters, and the popular press.

Getting Help/Support helps users understand what social services are intended to do, how they work, how to find a good provider, and how to be an effective and active consumer. Social services

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include those dealing with medical, legal, financial, disclosure, isolation, and sexuality issues. Getting Help/Support also includes a Referral Directory of area agencies that provide HIV-related services, and a Bulletin Board of meetings, events and news items.

Personal Stories are real-life accounts of people living and coping with AIDS/HIV infection. These stories were collected by trained journalists. Users can read short overviews as well as more detailed "expansions" on specific topics. Stories are indexed by both topic and demographic characteristics of the subject. Nearly 20 stories were available for the study.

**Communication Services.** Ask An Expert allows users to ask experts anonymous questions and receive confidential responses within 24 to 48 hours. Questions are answered by experts in HIV at the University of Wisconsin Health Service.

Discussion Group allows anonymous, non-threatening communication among people affected by AIDS/HIV infection. Several discussion groups were available. Groups were open only to study subjects and necessary CHESS staff. Message senders were identified by a code name, not the user's real name. A trained facilitator monitored the groups to keep discussion flowing smoothly.

**Analysis Services.** Decision Aid helps people through hard decisions. Users consider their various options and the factors that affect their choice, using either a tailored or a general decision aid program.

Action Plan helps users implement a new decision. It helps users through the process of preparing a plan for change, and helps users assess the likelihood of success of their plan, offering feedback on ways they can strengthen their prospects for success.

Risk Assessment allows users to assess their risk of exposure to, or transmission of, HIV. Users answer a series of detailed questions on behaviors that transmit HIV. CHESS then predicts the risk of exposure or transmission based on the reported behaviors.

The CHESS computers used in the study were PC's with 386sx microprocessors running at 16 MHz, 2 MB RAM, color VGA monitors, and 2400-baud modem. Printers were also provided. Computers were installed in the homes of HIV-positive people by a staff member who conducted a one-hour introduction and tutorial for each user. No incentives were offered for system use.

Thus, CHESS was conceived of as an integrated system with a real variety of services, attempting to recognize both that needs vary between individuals, and that individuals have complex and shifting needs that potentially span multiple services.

## METHODS

One hundred and thirty-two subjects were recruited in two cohorts from among HIV-positive people obtaining health care in (1) Dane County or (2) Milwaukee County, Wisconsin, using brochures and mailings. Sources included HIV clinics and specialist physicians, AIDS service organizations, and gay social organizations. Subjects who returned completed pre-tests were randomly assigned to a control or experimental group. In this paper we report on CHESS use by the experimental groups only: 31 men and seven women in Dane County and 25 men and three women in Milwaukee County.

Experimental subjects in the first cohort were given CHESS computers to use in their homes for six months; subjects in the second cohort had CHESS for three months, so that data reported here will come from the pre-test and two-month post-tests that are fully comparable. Subjects were paid for each survey completed. The computer collected data automatically on the frequency and duration of use of each of the CHESS services.

**Subject Population**

The majority of respondents were 30-45 years old, with a substantial minority younger and very few older. Their educational level ranged widely, but the median and mode were "some college," which combined with high school graduates comprised 53% of the sample. Respondents were remarkably cooperative with the study. There were only four drop-outs and two deaths between the pre-test and two-month post-test reported here.

## RESULTS

CHESS was very heavily used by the experimental group: an average of 183 uses and 1246 minutes per user over nine weeks, or approximately 20 times per week and for about 138 minutes per week by each individual. (Since number of uses and amount of time are highly correlated, we will report only the number of uses.) Use varied considerably, of course, with five subjects using CHESS fewer than 20 times and the most active 20% all averaging more than four uses per day across the nine weeks.

Because the computers stored a detailed log of times of use and user choices between and within CHESS services, it was possible upon return of the computers to tally use of each of the three kinds of CHESS services and of the use of individual services within

the overall categories. The two Communication services, which used the modem to put the user in touch with other people, were the most heavily used, accounting for 67% of all uses. Within this category, Ask An Expert accounted for 8% and Discussion Group 60%, making it by far the most heavily used service of the system as a whole. While every participant used Discussion Group at least once, 21% used it fewer than 10 times. One the other hand, 29% used it more often than once a day, and the four most frequent users averaged three or more uses per day throughout the two months.

The four Information services of CHESS jointly accounted for 27% of total use, fairly evenly divided among them: 6% Questions and Answers, 9% Instant Library, 6% Getting Help/Support, and 6% Personal Stories. Overall, the three Analysis services were used least, accounting for 6% of all uses.

Given that HIV-positive individuals did use CHESS when it was available over a period of weeks in their homes, the remaining questions have to do with who used CHESS -- whether there are social status barriers to use and whether it is used by those who need it.

Table 1 summarizes 14 separate hierarchical regressions, each predicting a CHESS use measure using three blocks of variables entered in order. Based on their relatively fixed status and causal priority, the first block entered six demographic and living status variables: age, gender, education, whether the individual was living alone or with others, whether they were in a steady relationship, and whether they were religious.

A second block, tested to see whether it added significant variance to the prediction, contained two dummy variables of disease stage: none versus any HIV symptoms, and whether they had been given a diagnosis of full-blown AIDS. By adding these after the demographic variables, their contribution can be assessed independent of any association with the demographic variables.

After this, a third block of variables was added that described five characteristics of the individual's pre-test levels of physical and emotional health: degree of HIV-related limitation on physical functioning, feeling energy, experiencing negative emotions, having social support, and needing health information that is difficult or expensive to get.

Thus, for each of the three blocks, Table 1 presents only those variables (actually, the group or direction of the dimension) associated with greater use of that portion of CHESS, and the variance accounted for by the block of variables, in each case showing all relationships $p < .10$.

Despite being entered first, the six demographic variables accounted for less variance than might have been expected (an average of 17%), especially when compared to the five health situation variables (adding an average of 11%, despite following the earlier variables). Women used CHESS more overall, and were heavier users than men of Information and Communication services. Not being in a relationship was associated with greater use of several Information and Analysis services, but not with use of the Communication services. Age was related in opposite ways to use of two services. Education and religiosity were unrelated to CHESS use.

The second block, stage of HIV disease, is most notable in its lack of relationships and very small increment to R-squared (average .05). Users with a full AIDS diagnosis were perhaps more likely to use Decision Analysis, and the significant increment in R-squared for Communication services stems from nearly significant trends for both dummy variables, suggesting greater use of CHESS Communication services at earlier stages of HIV-positive diagnosis.

The third block, of individual health situation and perceptions, adds an average 11% additional variance to the equations. In some cases (especially for physical functioning and feeling energetic), the betas reverse the zero-order relationships, because these variables are correlated with AIDS stage and each other. A need for health information (agreeing that needed information is difficult to get for geographic, monetary or effort reasons) predicts more frequent use of Questions and Answers within the Information Services, and both Decision Analysis and Action Plan within the Analysis Services. Feeling energetic predicted more frequent use of Ask An Expert and longer use of CHESS overall, but people lacking energy were more likely to use Decision Analysis. And after accounting for demographics and AIDS stage, good physical functioning predicts more frequent use of Personal Stories, Decision Analysis, and Action Plan. Pre-test level of social support works in opposite directions for Discussion Group and Risk Assessment.

## DISCUSSION

CHESS was very heavily used by HIV-positive individuals given access to the system in their own homes. Users ranged widely across the system, but 60% of all use involved participation in the Discussion Group, leaving messages, reading replies, or just scanning through messages. That CHESS was

Table 1. Summary of Significant (p<.10) Predictors of Use of CHESS

| | Demographics | $R^2$ | | $R^2$ | | $R^2$ |
|---|---|---|---|---|---|---|
| **Frequency of use** | women+ | .10 | | .11* | | .10 |
| **Total minutes of use** | women*<br>younger* | .19+ | | .05 | feel energy* | .13* |
| **Information use** | no relationship** | .21* | | .02 | | .06 |
| Questions & Answers | women+<br>no relationship+ | .12 | | .03 | need info+ | .09 |
| Instant Library | no relationship* | .25* | | .01 | | .04 |
| Getting Help/Support | live alone*<br>no relationship | .21* | | .02 | | .02 |
| Personal Stories | women+ | .10 | | .06 | good phys. funct.* | .09 |
| **Analysis use** | no relationship** | .23* | | .03 | low energy+<br>need info* | .18* |
| Risk Assessment | older+<br>no relationship** | .32** | | .01 | good phys. funct.*<br>socially isolated* | .13+ |
| Decision Analysis | older* | .17+ | AIDS diagnosis+ | .06 | low energy* | .16* |
| Action Plan | live alone* | .09 | | .05 | good phys. funct.*<br>need info+<br>need info** | .18* |
| **Communication use** | women* | .12 | | .13* | good phys. funct.* | .12 |
| Discussion Group | women+ | .10 | | .12+ | social support+ | .13 |
| Ask An Expert | women* | .12 | | .05 | feel energy* | .11 |

+ = p<.10, * = p<.05, ** = p<.01

used so heavily as a means of anonymous connection to other individuals in similar circumstances speaks against the common sense idea that computers are coldly informative and that they separate people.

Much of the rest of CHESS use was spread evenly across the four Information services, closer to popular conceptions of computer-based systems. However, the differences between the services must be taken into account in comparing amounts of use.

Discussion Group encourages and rewards frequent use to check for replies to messages or to follow ongoing conversations, and it constantly provides serendipitous benefits as conversations continue to raise new topics, provide new insights, or offer support. In contrast, both Information and Analysis services contain discrete information, each piece of which is likely to be accessed only once or twice.

CHESS appears to have been remarkably successful at avoiding traditional selection biases of information systems. Those with more schooling were no more likely to use the system, and women, were actually heavier users than men. In fact, we would suggest that the relative scarcity and weakness of demographic predictors further suggest that the system had very broad appeal. Stage of AIDS illness was irrelevant to CHESS use, indicating that CHESS was useful across very different stages of the disease.

The health situation measures of physical and emotional health, needing health information that is difficult to obtain, and degree of social support are fairly strong predictors of CHESS use, considering that they appear after two other blocks of variables. This suggests that while most users initially experiment with most or all of the services, their use focuses with time on some components more than others. Heavier users of some components (particularly the Analysis services) can be characterized by their prior need for information and limitations of their physical functioning. Use of the Communication services is more general -- only one or two measures predict any difference in use. Use of the Information services is least predicted by health situation.

Overall, these patterns of use of the CHESS system are very encouraging. HIV-positive individuals used the system very heavily, demonstrating that a computer-based system can overcome barriers to health information and support. Because education proved no barrier to use and women actually used CHESS more than men, the system appeared able equally to serve both the "information rich" and the "information poor." And finally, CHESS' incorporation of Discussion Group and Ask An Expert allowed the computer to bring people together rather than driving them apart. This latter finding is especially crucial for health crises where geography, rarity or social stigma would otherwise make it difficult to locate others sharing the crisis and obtain social support. Breaking through this barrier may prove to be the largest of CHESS' accomplishments.

*Hi there!*
*I've been away a little while. Just moved some major things around in my life. You people out there made me realize that I don't have the time to just sit and die, feeling sorry for myself; or quoting scripture (like it's going to help!) I got out there and did something positive:*

*i. quit smoking*
*ii. exercise every morning*
*iii. got a new job (not minimum wage, but $35,000/year)*
*iv. got on a new high vitamin/mineral diet*
*v. informed by family and friends about being HIV, and if they didn't like/accept it they can all go to hell.*

*I FEEL WONDERFUL!! Thanks for your inspirations."*
*...a CHESS user from our study*

References


1. D. Aguilera Crisis Intervention: Theory and Methodology. CV Mosby Company, St. Louis, 1990.

2. G. Caplan Principles of Preventive Psychiatry. Basic Books, New York, 1964.

3. R.H. Moos, and J. Schaeffer "The crisis of physical illness: An overview and conceptual approach." In Coping with Physical Illness II: New Perspectives, R.H. Moos, Ed. Plenum Medical Book Company, New York, 1984.

4. P. Slovic, B. Fischoff, and S. Lichtenstein "Behavioral Decision Theory." Annual Review of Psychology, 1977; 28:1.

5. K. Bosworth and D.H. Gustafson "CHESS: Providing decision support for reducing health risk behavior and improving access to health services." Interfaces, 1991; 21:93.

6. D.H. Gustafson, K. Bosworth, R.P. Hawkins, E.W. Boberg, and E. Bricker. "CHESS: A Computer-based support system for providing information, referrals, decision support and social support to people facing medical and other health-related crises." Proceedings of the 16th Annual Symposium on Computer Applications in Medical Care. 1992; 161.

7. C. Salmon "Critical considerations in information campaigns: Balancing social effects and social responsibility." In Information Campaigns, C. Salmon, Ed. Sage, Newbury Park, CA, 1989.